Louisiana Department of Health and Hospitals
Medicaid Long Term Services and Supports RFI
CQL Response to Request for Information (RFI)
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GENERAL INFORMATION

CQL| The Council on Quality and Leadership
100 West Road, Suite 300
Towson, MD 21204
410.583.0060
www.c-q-l.org

Cathy Ficker Terrill, President and CEO
cfterrill@thecouncil.org

CQL |The Council on Quality and Leadership (CQL) is private not for profit 501(c) (3) corporation that provides international leadership in the definition, measurement, and improvement of quality of life for people with intellectual and developmental disabilities, people with mental illness and substance use disorders, and older adults.

CQL provides services throughout the United States, Canada, Ireland, Australia and New Zealand

CQL has been in continuous operation since 1969. Between 1969 and 1979, CQL operated under the auspices of the Joint Commission on Accreditation of Hospitals (now JCAHO). In 1979, CQL incorporated in the District of Columbia as a private, independent not-for-profit organization.

CQL emerged in the late 1960's from national efforts to improve conditions in public institutions serving people with disabilities. CQL established the first set of standards and performance indicators for children and adults that were later adopted as Federal Standards by the Health Care Financing Administration – (HCFA-now the Centers for Medicare and Medicaid Services-CMS) for use in ICFs/MR. Federal regulations published in 1978 reflected the 1971 and 1975 CQL *Standards*. This same pattern repeated itself a decade later as the Health Care Financing Administration, in revising the ICF/MR regulations, drew heavily from CQL's 1984 *Standards for Services for People with Developmental Disabilities*.

CQL's standards were also incorporated in the historic Wyatt v. Stickney court decision and the federal courts later incorporated CQL's standards into legal settlements in Texas, North Dakota, California, Arkansas, West Virginia and other states.

Today, CQL in an international not for profit organization, governed by a 20 person Board of

Directors, representing people with disabilities and mental health challenges, advocacy organizations, service providers, and professionals.

- **CQL Vision** – A world of dignity, opportunity and community for all people.
- **CQL Mission** – To provide leadership to improve the quality of life for people with intellectual and developmental disabilities, people with mental illness and substance use disorders and older adults.
- **CQL Work** – Demonstrated international leadership for over 40 years in the definition, measurement and improvement of quality of life people with intellectual and developmental disabilities, people with mental illness and substance use disorders and older adults.

CQL has continuously developed, tested and applied new measures and quality indicators in its own accreditation, certification, and monitoring and review work. For decades, CQL has worked in collaboration with both federal and state agencies to evaluate and monitor quality by designing and/or applying relevant national and local program measures and review methods.

Currently, CQL offers three metrics that are linked to personal quality of life outcomes. CQL has demonstrated the validity of these metrics, conducted research on the metrics for over two decades, and developed several national databases.

1. Basic Assurances® (addresses Protections, Health and Safety, Rights and Environmental Supports)

The Basic Assurances® define safeguards in health, safety, and security. *The Basic Assurances®* serve as formula for service planning, a guide to implementation, and a method for measuring the health, safety, and security for individuals.

The *Basic Assurances®* are both person-centered and system-linked. While the *Basic Assurances®* require systems and policies, and procedures, they measure the effectiveness of systems, policy, and procedure by actual practice, person by person. The *Basic Assurances®* were originally published in 2005 based on data and research from accreditation reviews with the *Personal Outcome Measures®*. After a decade of additional research with data and information from 302 organizations, CQL has identified the 23 indicators that best predict performance in health, safety, and security.

2. Key Factors and Success Indicators in Person-centered Excellence
(addresses Individualized Services, Planning, and Service Delivery; Supporting Family, Natural Supports and Community Connections, Community Inclusion; Workforce Performance; Quality Improvement Plan; Governance and Leadership)

CQL launched the *What Really Matters* initiative in 2008 to identify evidence-based practices that promote person-centered excellence. CQL conducted international research with self-advocates, leading researchers and practitioners, families, provider organizations, and state and

federal officials. CQL conducted an international Delphi Panel Survey, focus groups, a review of the literature in intellectual and developmental disabilities, and numerous stakeholder group meetings. CQL contracted with national experts and conducted field tests to finalize the eight key factors and 34 success indicators.

The Key Factors and Success indicators provide a road map that enables organizations to transform services from the traditional service and support programs to real individualized and person-centered services that promote personal quality of life.

3. Personal Outcome Measures®
(Addresses effectiveness of services and supports on the person and/or family receiving services)

CQL introduced the *Personal Outcome Measures®* in 1993 following a three-year period of development, research, and field trials. The research has been published in numerous peer reviewed journals and was facilitated by a contract with the Health Care Financing Administration (now CMS) to develop and manage a national *Personal Outcome Measures®* database. The database now contains over 8200 valid and reliable interviews gathered during accreditation reviews at organizations throughout the United States.

The *Personal Outcome Measures®* are unique because:

- Unlike economic or social indicators, the *Personal Outcome Measures®* identify and define, measure, and improve quality *from the individual person's point of view*. Each person is a unique sample of one. There is no standardized norm for the outcomes. Each person has, for example, her or his own definition of respect, community, and friends.
- The *Personal Outcome Measures®* are neither self-reported, a measure of satisfaction, or the report from a surrogate. Rather, the *Personal Outcome Measures®* provide an analysis of all the information gathered during personal interviews and meetings with family, friends, and staff, and then, following a specific logic chain, trained and certified raters make decisions about whether the outcome, as defined by the person, is present or absent in the person's life.
- The *Personal Outcome Measures®* lead into important questions about supports and services that facilitated specific outcomes. Unlike other quality of life measures and quality indicators, the *Personal Outcome Measures®* establish a connection between the outcome, as defined by the person, and the specific support that facilitates the outcome or that is needed to facilitate the outcome in the future. Thus, there is a clear path between the definition and measurement of quality and quality performance improvement.

PERSONAL QUALITY OF LIFE AND MANAGED LONG TERM SERVICES AND SUPPORTS

The continuing research on managed care suggests that extending the basic principles of managed care (models, costs and implementation) to Medicaid managed care and managed long-term supports and services (MLTSS) will be challenging.

Medicaid managed care can be complicated. States, Managed Care Organizations (MCOs), and MLTSS providers are being challenged to establish standards and metrics for state and MCO systems performance.

While recognizing these challenges, CQL urges all potential managed care participants, their families, supporters, providers and public officials to pay attention to focus on the key design and operational feature of managed care – measuring the impact of the Managed Long Term Services and Supports on the quality of life for each individual.

The Kaiser Commission on Medicaid and the uninsured recently noted that:

> *Specialized measures of access and quality and robust monitoring efforts are needed to ensure access, coordination and satisfactory patient experience across the range of services and supports needed by individuals with disabilities. Widely used quality measure sets, such as the Healthcare Effectiveness Data and Information Set (HEDIS) and the Consumer Assessment of Healthcare Providers and Systems (CAHPS), do not take into account, or include targeted measures that reflect, the special needs of people with disabilities. Nor have standard quality measures for LTSS been developed, a problematic gap in the context of efforts to integrate management of LTSS and acute health care.*
> http://www.kff.org/medicaid/upload/8278.pdf

The Center for Health Care Strategies, Inc. released a report in November 2010 that identified the "Top Ten Mileposts for reaching Effective Managed Long-Term Supports and Services Delivery". The report stressed that performance measurement is not possible without LTSS-focused measures that stress individual consumer outcomes.

> http://www.chcs.org/publications3960/publications_show.htm?doc_id=1261188

The Long Term Quality Alliance recently issued its Quality Measurement Workgroup Report on adult recipients of long-term services and supports. After reviewing the array of clinical and functional outcome measures, the authors noted:

> *Thus, further development of measures is necessary to assess aspects that contribute to quality for individuals and their families that are broader than clinical outcomes, including measurement of outcomes such as quality of life, autonomy, relationships, compassion, social supports, and emotional well-being.*
> (http://www.ltqa.org/2011-12-23-measurement-opportunities-gaps.html)

The National Council on Disability (NCD) released a report on "Managed Care and Disability" and in a discussion of basic principles and recommendations to CMS, the NCD noted the necessity of evaluating service patterns and trends, provider performance, provision of

identified services and supports and the responsiveness of provider networks. The report stressed the importance of measuring key participant outcomes.

Recommendations to CMS can be found at:
http://www.nasddds.org/pdf/CMSMANAGEDCARENCDRECOMMENDATIONS 1.pdf
The Guiding Principles are available at:
http://www.nasddds.org/pdf/MANAGEDCARENCDPRINCIPLES 1.pdf

Service quality and systems performance are important. Managed care will place new accountability requirements on the system. This discussion around managed care provides the opportunity to finally shift accountability and performance measurement from the services that organizations and systems provide to the personal quality of life outcomes for people receiving the services. We have now reached the point where we can assert that the most meaningful measure of quality in LTSS is the quality of life experienced by the individual in the system. In LTSS, where people may receive services for extended periods of their lives or (in the case of some people with intellectual and developmental disabilities) their whole lives, personal quality of life is the metric that matters most to support recipients and their families.

For CQL, the emphasis on personal quality of life measures as a fundamental requirement for managed long-term supports is striking.

CQL'S DEMONSTRATED CAPACITY AND CAPABILITY

CQL demonstrates the following four (4) organizational capabilities:

(1) Design of Quality Metrics, Standards, and Measures

CQL has provided unequaled leadership in the design of quality metrics, standards, and measures that have been adapted, replicated, and incorporated into federal, state, and provincial requirements throughout the world. CQL's early standards were incorporated into federal Medicaid standards and regulation for the Intermediate Care Facility Program. The *Personal Outcome Measures*® have been adapted and written into state, provincial, and national standards in New Zealand, Australia, Ontario, Canada, and by numerous state developmental disability agencies in the United States.

(2) Provision of Training, Technical Assistance, and Consultation

CQL has demonstrated expertise in building internal capacity in the design and implementation of services and supports that result in personal quality of life attainment for self-advocates and their families. CQL has provided these capacity building services at both the provider and state agency level. CQL has partnered with numerous public sector agencies across the U.S. through a range of training and technical assistance projects to build the agency's internal capacity for ongoing quality management. CQL certification programs are designed to sustain competencies, leadership, organizational change, and quality initiatives. Some examples:

- Development, Design and Implementation of Local Standards/Measures and Review Methods
  - Incorporated CQL's *Basic Assurances*® into the State of Alabama's Division of Mental Retardation's Administrative Code, Chapter 580-5-31
  - Incorporated CQL's *Personal Outcome Measures*® into the Texas Quality Assurance and Improvement System (QAIS)

- Data Collection and Analysis
  - Personal Outcome Measures® interviews with over 300 individuals (annually) receiving services from the state of Florida Department of Families and Children (now APD) who were about to experience a change in service delivery
  - Conducted Personal Outcome Measures® interviews as subcontractor to federally recognized Quality Improvement Organizations (QIO) in Florida (Delmarva Foundation), Wisconsin (Metastar), and Indiana (Liberty)

- Training and Technical Assistance – Building Internal Systems Capacity
  - Quality assurance personnel development projects for IDD Departments in Colorado, Connecticut, Delaware, Florida, Illinois, Louisiana, Minnesota, Nevada, North Carolina, Pennsylvania, South Carolina, Tennessee, South Dakota, Kansas, Mississippi, and Utah
  - Certified Quality Analyst training for state personnel in Illinois, Iowa, Kansas, Mississippi, South Carolina, and South Dakota
  - eLearning courses through partnership with Essential Learning

(3) Independent Third-party Evaluation

CQL has demonstrated expertise in program evaluation, monitoring, data analysis, and quality assurance. CQL has demonstrated an independent, third-party evaluation capability of objectively and reliably applying the standards and methods mandated in federal and state requirements, including:

- CQL Accreditation and Memoranda of Understanding
  - Continuous operation of nation-wide accreditation program since 1970
  - Recognized by state and federal courts as the accepted methodology for quality assurance compliance
  - Deemed status approval for CQL Accreditation in states: Alabama, Georgia, Illinois, Indiana, Iowa, New Mexico, North Dakota, Maryland, Missouri, Massachusetts, and South Dakota

- Third-party, Independent Review
  1. Federal certification reviews in Alabama, Arizona, District of Columbia, Iowa, and Nevada
  2. Nation-wide Federal Look-Behind Surveys for CMS

3. Third-party independent reviews of long-term care in California, Texas, and Washington
4. Independent evaluation of providers in the HCBS Waiver program for the Kentucky Department for Medicaid Services

- Investigations
  - Follow up and investigation of complaints or reports of abuse, neglect, mistreatment, or exploitation involving Kentucky HCBS Waiver providers.
  - Legal review and follow up on incident reports for Office of Inspections and Monitoring in the District of Columbia

- Demonstrated Expertise in Data Analysis
  - Established the *Personal Outcome Measures®* Database in 1993 – the first database on personal quality of life outcomes (with initial funding support from CMS); CQL has collected, analyzed and published *Personal Outcome Measures®* Database findings on an ongoing basis
  - Submitted of annual data analysis to public agencies in North Dakota, South Dakota, North Carolina, Georgia and Illinois
  - Submitted annual and final contract reports to CMS on the Look Behind Surveys of over 500 ICFs/MR

(4) Collaboration with Private and Public Organizations

CQL has developed partnerships and collaborations with a range of public and private organizations in the United States, Canada, Ireland, Australia, and New Zealand. In some cases, we have worked with private organizations such as the Finger Lakes Collaborative in New York State, the Outcomes Network in Ireland, and The Mosaic Collaborative in the United States. In the public sector, CQL has developed a model Memorandum of Understanding (MOU) with state Developmental Disabilities agencies that delineates CQL and State responsibilities for integrated quality management initiatives within the state by both parties.

● CQL Partnerships with the State Agency as a Direct Contractor

Partnership models include:

- CQL conducts onsite review work, using state requirements, reports, analysis, recommendations
- CQL conducts onsite review work, using CQL metrics, reports, analysis, recommendations
- CQL trains and monitors state employees in use of CQL metrics
- CQL develops or revises state-specific metrics
- CQL designs or revises state-specific review and monitoring methodologies
- CQL and State agree to MOU regarding accreditation and state oversight

● CQL Partnerships with QIO/QIO-Like Organizations as a Sub-Contractor

Partnerships include:

- Delmarva – multi-year project in Florida
- Liberty Healthcare – multi-year projects in District of Columbia, Indiana, Kentucky, and Nebraska
- MetaStar – multi-year project in Wisconsin

CQL AND LOUISIANA MANAGED LONG TERM SERVICES AND SUPPORTS

CQL offers the State of Louisiana a variety of quality management options designed over 45 years of leadership in the field of human services. We can integrate our core capabilities – instruments, independent third-party review, and cooperative partnerships – in a manner that will best promote the goals and outcomes of Long Term Services and Supports for persons enrolled in Louisiana Medicaid.

After 20 years of personal quality of life measurement and systems improvement, and in looking forward to the implementation of managed LTSS, CQL recommends the following strategies:

1. Employ uniform metrics throughout the state and across all MCOs. Comparative outcome analysis and recognition of successful performance in facilitating personal quality of life is a vital part of managed care.

2. Employ measures that are person-centered and not focused on programs, service settings or funding criteria. Broaden the definition of "standardized measures of quality". CQL has demonstrated that it is possible to aggregate data on items that are personally defined rather than standardized in the traditional sense.

3. Structure state MCO contracts with a requirement for uniform, valid, and reliable reporting and evaluation through the use of personal outcome measures. CQL's *Personal Outcome Measures*® (for personal quality of life) are based on 20 years of data collection and analysis, inter-rater reliability methods, and published research in peer reviewed journals.

4. Employ measures that can be applied across different populations, services, and geographical regions.

5. Employ quality measures that also identify specific supports and services that are facilitating health status, functional capabilities, and personal outcomes. Without the linkage between outcomes and services, quality measurement remains measurement only and cannot be connected to improved quality management at the organizational level.

6. Employ quality measures that are efficient, require low administrative and overhead supports, and that can be interpreted at multiple levels in the overall system, including the local provider level.

7. Ensure that clinical, functional and personal outcomes are integrated.

8. Employ an independent third-party to review the provider use of the agreed-upon metrics, standards, and performance measures to evaluate the consistent and uniform valid applications.

9. Provide hands-on experiential training to providers in the use of the metrics, standards, and performance measures.

10. Use consistent metrics over time to be able trend for changes and improvements in quality of life and quality of service at the individual, provider and systems level.

CQL recommends that Long Term Services and Supports for persons enrolled in Louisiana Medicaid be evaluated on the basis of outcomes achieved by the recipients of supports and services. The managed care organization will be successful as it shifts the attention from compliance with process and organizational outputs to responsiveness to the person receiving services and his or her family and the achievement of personal outcomes for the person receiving services and supports.

CQL's Personal Outcome Measures®

With the ***Personal Outcome Measures***®, CQL has for twenty years demonstrated a three-part process to measuring the linkage between personal outcomes and the support services identified in the person-centered plan that facilitate that outcome:

1. First, identify each individual's definition of his or her ***Personal Outcome Measures***®.
2. Then, determine whether the outcomes, as defined by the person, are present.
3. Finally, through conversations with the person, his or her family, staff, and volunteers identify the specific individualized services or supports that are facilitating that outcome for the person. Then ask the questions: Is that support identified in the plan? If not, why is the organization providing supports that don't address the person's priority outcome?

CQL provides the only personal quality of life metric that links the person's priority outcomes with an exploration of the specific supports or services that currently facilitate the outcome or that must be provided in the future to facilitate the outcome. Other quality of life scales and social indicators can produce scaled scores, but the ***Personal Outcome Measures***® is the only metric that defines quality from a personal perspective, measures the presence of quality in an objective manner, and then identifies the unique and specific supports that are facilitating the personal outcome. CQL's ***Personal Outcome Measures***® are:

MY SELF

People are connected to natural supports.
People have intimate relationships.
People are safe.
People have the best possible health.
People exercise rights.
People are treated fairly.
People are free from abuse and neglect.
People experience continuity and security.
People decide when to share personal information.

MY WORLD

People choose where and with whom they live.
People choose where they work.
People use their environments.
People live in integrated environments.
People interact with other members of the community.
People perform different social roles.
People choose services.

MY DREAMS

People choose personal goals.
People realize goals.
People participate in the life of the community.
People have friends.
People are respected.

CQL can offer the ***Personal Outcome Measures***® as a uniform state-wide benchmark metric to evaluate the adequacy of person-centered planning. The ***Personal Outcome Measures***® offers three unique advantages in determining the adequacy of person-centered plans:

1. The ***Personal Outcome Measures***® enable each person to identify and define their own meaning for each of the outcomes. The ***Personal Outcome Measures***® consider each person as a unique sample of one. They are personal.

2. When used as an evaluation method, the ***Personal Outcome Measures***® determine whether the outcome, as defined for the person, is present. This measurement is objective and based on a valid, documented methodology that has been published in peer reviewed journals. (We noted in the journal *Mental Retardation* that "We have demonstrated that it is possible to aggregate data on items that are personally defined rather than standardized in the traditional sense.) Thus, the definition of adequacy of the plan is linked to the outcomes of the plan for the person.

3. For each of the 21 ***Personal Outcome Measures***®, the evaluator identifies the individualized support or service that is facilitating the outcome as defined by the person. This methodology stipulates that the identification of the outcome must precede the design and delivery of the individualized process. If all people had the same outcome, defined their outcomes the same, or learned and responded to the world in the same manner, then we could identify processes that would lead to individual results. But peoples' priorities are different; people change over time; and their methods of communication, learning, and adaptation are different. As a result, the ***Personal Outcome Measures***® measure the link between personal priorities, individualized supports, and outcomes.

This explicit connection between the personally defined quality of life outcome, the identification of the unique services and supports that facilitate the outcome, and the measure of attainment of the outcome is a unique feature of the ***Personal Outcome Measures***®. No other quality of life scale or set of indicators provides such an individualized approach and/or identification of and linkage to specific services and supports. The ***Personal Outcome Measures***® support the person-centered planning process, the measurement and evaluation of quality results, and the identification and budgeting of resources that facilitate the quality of life outcomes.